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Testimony: Proposed Regulations Relating To Aversive Behavioral Interventions

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The New York Civil Liberties Union

Before

The Office Of Vocational And Educational Services For Individuals With Disabilities Of The New York State Education Department

Concerning Proposed Regulations Relating To Aversive Behavioral Interventions

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My name is Beth Haroules. I am a Staff Attorney at the New York Civil Liberties Union (NYCLU) and one of plaintiffs' counsel in *NYSARC, Inc. v. Pataki*, more commonly referred to as the *Willowbrook* case. The NYCLU is the New York affiliate of the American Civil Liberties Union. The NYCLU has long been devoted to the protection and enhancement of those fundamental rights and constitutional values embodied in the Bill of Rights. In the forefront of those efforts has been our defense of the rights of those individuals with mental retardation and/or developmental disabilities under the Federal Constitution and the New York State Constitution.

The NYCLU, with others, commenced the *Willowbrook* lawsuit in 1972 to correct the inhumane institutional conditions suffered by the residents of the infamous *Willowbrook* State School. We successfully argued that the United States Constitution guaranteed such individuals the rights to equal protection and to due process in the decision to institutionalize them; freedom from abuse and unreasonable restraint within the institution; a clean, sanitary environment; nutritious food; adequate clothing; decent medical care; protection from harm; and appropriate treatment or rehabilitation to improve their mental condition or to increase their skills.

After the *Willowbrook* Consent Judgment was entered on May 5, 1975, the focus of the litigation turned to advocacy for the development of standards guiding community-based services in the least restrictive setting appropriate to the individual as a means to advance social justice for people with mental retardation and developmental disabilities. The standards established have included the right of New York's mentally retarded citizens generally to be free from the imposition of aversive behavioral controls and seclusion and restraint techniques. And, for the past quarter century, the *Willowbrook* entitlements have set the standard for the developmentally disabled in this state and many others.

But, in June, the New York Board of Regents took an enormous step backward when it approved "emergency regulations" that permit New York State schools to use, on a "child-specific" basis, aversive behavioral interventions and restraint and seclusion techniques, including time-out rooms, as consequences for behavior of children with disabilities who attend New York State schools. These regulations legitimize the use of aversive behavioral interventions, restraints and time out/isolation and seclusion rooms in every school district and at every state-operated residential school and state-approved private school in the entire State of New York. The NYCLU litigated the *Willowbrook* case to end the torture and dehumanization of individuals with disabilities attending "school" in New York State. With hastily passed emergency regulations, the Board of Regents has turned the clock back to a time when children with mental or emotional disorders were routinely punished for behaviors they generally cannot control.

These regulations now authorize New York State educators to subject children with disabilities to noxious, painful, or intrusive stimuli or activities intended to induce pain. Personnel would be authorized to apply ice to children's skin; to hit, kick, pinch or strangle them; to perform deep muscle squeezes; or to subject them to electric skin shock, and painful water sprays or inhalants such as amonia. They could also withhold sleep, shelter, bedding, bathroom facilities, meals, water, or clothing from children whose behavior was inappropriate or inconvenient. They could also alter fundamental food staples, putting urine in water or Tabasco sauce on food, for example. Children could routinely be put into restraint in non-emergency situations. Children could also be confined to "time out rooms" from which they could not exit and in which they would stay unsupervised.

A wide range of safe positive methods are available which are not only more effective in managing or redirecting "problem" behaviors, but which do not inflict pain on, humiliate, or dehumanize individuals with disabilities. The practice of subjecting individuals with disabilities to what are termed "aversive interventions" to control behaviors that are associated with their disabilities is outmoded and ineffective. Aversive behavioral interventions and seclusion and restraint practices, including time out rooms, are punishment and control techniques. These techniques serve no therapeutic purpose, much less any educational purpose. They are an extremely poor substitute for staff and provision of other resources which are necessary to provide appropriate treatment and supports for persons with mental retardation. As punishment and control techniques, these behavioral "interventions" can be and often are easily abused -- as they were at the Willowbrook State School.

The Centers for Medicaid and Medicare Services (CMS) prohibits non-emergency restraint use in facilities receiving federal funding, as does the Children's Health Act of 2000. Most states have prohibited non-emergency restraints and other aversives for years. All mainstream state and national disability rights organizations oppose the use of painful aversives and seclusion and restraint techniques. The accepted norm is: if it cannot be done to non-disabled children or adults then it cannot be done to vulnerable individuals with disabilities. Imagine the outcry if a teacher tied a non-disabled student down or methodically squirted water into her face and up her nose to "change her behavior" in the classroom. Consider how quickly the police would be called and ACS or another county youth protection agency would intervene if a parent administered electric shocks with a cattle prod to his child to make him "behave" at the playground. Children and adults with disabilities deserve the same compassion and protection.

New York State knows better and can do better than this. While these emergency regulations set forth a regime where the child's record may be "papered" with behavioral justification and there are several layers of review of the articulated need for aversive interventions prior to such use, no

amount of regulating levels of approval, oversight and monitoring, and parental consent can remedy the fact that there is no place for aversive behavioral interventions and seclusion and restraint techniques in any educational milieu. The NYCLU urges the Board of Regents to revoke these regulations and to prohibit completely the use of aversive behavioral interventions and seclusion and restraint techniques in all New York State public and private schools.

Aversive Behavioral Interventions and Seclusion and Restraint Techniques Are Abusive, Barbaric and Outmoded and Serve No Therapeutic Purpose -- The Mandated "Gold Standard" in Educating Children with Emotional and Behavioral Problems is Positive Behavioral Interventions and Supports (PBIS)

The use of aversive behavioral interventions and restraint and seclusion techniques on children with cognitive and other mental disabilities is especially unacceptable given the unique functional characteristics of these persons. Behavioral programs using aversive behavioral interventions and restraint and seclusion techniques focus only on the behavior itself, and do not consider the core issues causing the perceived unacceptable behavior. Aversive behavioral interventions and restraint and seclusion techniques also ignore the neurological context of behavior, frequently targeting aspects of the disability that are not under the individual's control.

The primary characteristics which distinguish persons with mental retardation from the rest of us are limitations on their functional and intellectual capacities. These limitations vary from one individual to another and are the fundamental consideration in the design of treatment strategies and supports. Research on the function of behavior problems in persons with severe disabilities demonstrates that some behaviors may be perceived by others to be undesirable but may actually represent a response to environmental conditions and, in some cases, a lack of alternative communication skills. Services should include behavioral and environmental systems of supports that will enhance the person's independence and self-determination (ability to make choices). Such an approach is administratively complex. It requires an investment of time and resources including intensive staff involvement and creation of appropriate environmental supports. Because the functional capabilities of individuals with mental illness and mental retardation constantly change in response to environmental and other factors, programs of services and supports require continual reassessment and adjustment.

Administratively, it might appear to be easier to use punishment and control techniques, such as aversive behavorial interventions and seclusion and restraint techniques. In reality, the use of such interventions contradicts and undermines the success of appropriate long-term treatment approaches for persons with mental illness and mental retardation. Aversive behavioral interventions and restraint and seclusion techniques are merely a substitution for staff and provision of other resources which are necessary to provide appropriate treatment and supports for persons with mental disabilities. As such, aversive behavorial interventions and seclusion and restraint techniques are used merely for administrative convenience and this use can be easily abused.

In 1997, Congress amended the federal law that mandates "free and appropriate education" for all children with disabilities, the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 614 (d)(3)(B)(i). The law explicitly mandated that school districts focus on prevention of and early intervention in problem behavior. As the U.S. Department of Education stated in its comments on the amendments' implementing regulations, "IDEA now emphasizes a proactive approach to behaviors that interfere with learning." The U.S. Department of Education noted that a "key provision" of IDEA '97 mandates using positive behavioral interventions and supports to help

children with disabilities avoid engaging in behaviors that result in disciplinary actions and prevent their participation in the classroom. In a recent report, the renowned Bazelon Center for Mental Health Law noted that:

> One of the most significant changes targeted services and supports for children and youth with emotional and behavioral problems. The IDEA '97, as the amendments are known, specifically mentioned two important tools for addressing these problems: Functional Behavioral Assessments (FBAs) and Positive Behavioral Interventions and Supports (PBIS). The inclusion of these concepts in the statute was both revolutionary and unremarkable—*revolutionary because the federal government had never before explicitly required use of these practices, and unremarkable because professional literature reports the successful use of these techniques for more than 25 years.*

See Bazelon Center for Mental Health Law (2003). *Suspending Disbelief: Moving beyond punishment to promote effective interventions for children with mental or emotional disorders.* Washington, D.C. (emphasis supplied).

Bazelon's report is instructive. It emphasizes the fact that to help school districts implement the new IDEA mandate, the federal government established the OSEP Technical Assistance Center for Positive Behavioral Interventions and Supports, which has several partner sites around the country. Bazelon points out that these sites review and make accessible the professional literature on FBAs and PBIS, conduct research on the effectiveness of PBIS, and provide significant technical assistance at the request of school districts. One site, for example, has worked with schools to develop school-wide behavior management programs that are not limited to students with disabilities and has studied the positive impact on school-wide discipline and other beneficial effects, such as improved attendance.

PBIS are "procedures based on understanding why challenging behavior occurs"—i.e., what function does the behavior serve to the child using it? According to the OSEP Technical Assistance Center, PBIS is "first and foremost an ongoing problem-solving process." It includes assessment leading to the design of effective approaches that will reduce impeding behavior(s) and/or teach new skills and the development of "supports" to help the child maintain the resulting positive changes in behavior. Importantly, "[i]nterventions that result in humiliation, isolation, injury and/or pain would not be considered appropriate."

According to OSEP's Technical Assistance Center on PBIS, a significant body of research has "demonstrated the efficacy of PBIS in addressing the challenges of behaviors that are dangerous, highly disruptive, and/or impede learning and result in social or educational exclusion," such as self-injury, aggression, and property damage.

Aversive Interventions and Non-Emergency Restraint and Seclusion Techniques Violate Individual Rights.

As noted above, the NYCLU does not believe there are justifiable reasons for using aversive interventions, and non-emergency restraint and seclusion techniques. The use of aversive

interventions, non-emergency restraint and seclusion techniques under the guise of therapeutic or educational interventions create risk and unnecessarily take away basic rights. There is a lack of evidence that aversive techniques offer a safe means of teaching desirable, self-directed behavior that a child can maintain over the long term. Safe, positive methods of changing and redirecting behavior are well documented. Evidence shows them to be successful regardless of the child's diagnostic label, degree of disability, or severity of behaviors. The responsibility to employ best practices, and the obligation to do no harm in treatment require that the least dangerous, least intrusive, and least restrictive methods always be used. Moreover, the use of procedures may cause physical and/or psychological harm, are dehumanizing and restrict the individual's right to dignity and self-determination.

Under all of these circumstances, we believe that the use of aversive interventions and non-emergency restraint and seclusion techniques is violative of an individual's equal protection and due process rights and constitutes demeaning, demoralizing, and dehumanizing treatment, rising to the level of cruel and unusual punishment under the Eighth Amendment to the federal Constitution and Article 1, Section 5 of the New York State Constitution. We also believe that such practices violate several international human rights conventions, including the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the Convention Against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment.

Expansion Of The Use Of Aversive Behavioral Interventions And Restraint And Seclusion Techniques Will Undermine New York State's Leadership Role In Protecting The Rights Of Individuals With Mental Disabilities

As noted above, there is now broad national consensus amongst mental health experts that the use of aversive behavioral interventions and restraint and seclusion techniques serve no therapeutic value. And, restraint techniques can only be justified, if at all, as an extreme, temporary emergency safety measure in response to imminent danger to that person or to others.

The current national trend is toward reducing and, ultimately, eliminating the use of aversive behavioral interventions and restraint and seclusion techniques in behavioral health care settings. New York State has long been recognized to be a national leader in this area. In a September 1999 report, "Improper Restraint or Seclusion Use Places People at Risk," and in its October 1999 testimony before the United States Senate Finance Committee, "Extent of Risk From Improper Restraint or Seclusion is Unknown," the United States General Accounting Office ("GAO") praised New York State's efforts to protect individuals with mental disabilities who may be subjected to restraint or seclusion and to reduce the frequency of the use of these interventions. The GAO, in its report and testimony, pointed to the New York State experience as a model for national reforms to ensure the safety and well-being of individuals with mental disabilities.

Landmark national legislation, modeled on New York State's, was passed in 1999 and has led, overall, to tighter controls on the use of restraints in all mental hygiene facilities in this country. See "Patient Freedom from Restraint Act of 1999," 42 U.S.C. §§ 591 and 595, now codified at 42 U.S.C. § 290ii. Federal and State mental health authorities have since furthered the development and implementation of policy change and the active pursuit of the reduction and ultimate elimination of restraint and seclusion techniques.

Yet, at the same time that the use of aversive behavioral interventions and restraint and seclusion techniques is being increasingly challenged, if not rejected, by the field's leaders and policy makers,

the "emergency regulations" endorse the expansion of its use.

Specific Problems with the Regulations As Drafted that Will Enhance the Likelihood of Abuse of Students with Disabilities

Without conceding that there is any place for the imposition of aversive behavioral interventions and non-emergency restraint and seclusion techniques in New York State's schools, we offer the following commentary with respect to certain specific provisions of the emergency regulations.

"Appropriate Supervision" of Staff

Section 200.22(f)(4) provides that "[a]ny person who uses aversive behavioral interventions on students shall receive appropriate supervision, including direct observation." Section 200.6 of the Regulations indicate that "when a remedial service is included in the individualized education program, such service shall be provided by appropriately certified or licensed individuals." Is a behavioral intervention plan including aversives a "remedial service" ? What is "appropriate supervision" of school personnel who are using "noxious, painful, intrusive stimuli or activities intended to induce pain" including electric shock, hitting, and strangling? What is "appropriate supervision" of school personnel who "withhold sleep, shelter, bedding, bathroom facilities, clothing, food, or hydration" or who must "intentionally alter[...] staple food or drink in order to make it distasteful" to a child ? There is no requirement that staff, much less supervisors, possess appropriate clinical background or training.

"Research-based Aversive Behavioral Interventions"

Section 200.22(f)(2)(v) mandates that schools must use aversive behavioral interventions that are "peer-reviewed research based practices." Yet, the Department of Education itself has been unable "to identify any peer-reviewed research which supports" the range of aversive interventions used most extensively (i.e., manual and mechanical movement limitation; contingent food programs and electrical stimulation). See here [1]. We submit that there is, in fact, no peer-reviewed research based aversive behavioral interventions because these interventions are widely perceived to be both ineffective and inhumane and dehumanizing.

"Humane and Dignified Treatment"

Section 200.22(f)(2)(i) mandates that a program that uses aversive behavioral interventions on a child "shall provide for the humane and dignified treatment of the student and for the development of such student's full potential at all times." The section further mandates that "The program shall promote respect for the student's personal dignity and right to privacy and shall not employ the use of threats of harm, ridicule or humiliation, nor implement behavioral interventions in a manner that shows a lack of respect for basic human needs and rights."

It is exceedingly difficult to understand how a program that may include electric shock, punching, strangling, withholding sleep, shelter, bedding, bathroom facilities, clothing, withholding meals, limiting essential nutrition or hydration and intentionally altering staple food or drink in order to make it distasteful to a child, "provide[s] for the humane and dignified treatment of the student" or "promote[s] respect for personal dignity and right to privacy." The regulations provide no guidance in this regard.

"Time Out Rooms"

Section 200.22(c)(3) permits time out rooms to be used without a "behavioral implementation plan that is designed to teach and reinforce alternative appropriate behaviors" in connection with an "emergency intervention." "Emergency intervention" is undefined and no strictures are placed upon the use of the time out room under such circumstances. Why does this particular exception not swallow the other provisions of this subsection?

Section 200.22(c)(4) mandates that "parents shall be informed prior to the initiation of a behavioral intervention plan which will incorporate the use of a time out room." This section suggests that no parental consent is required for the use of a time out room.

Section 200.22(c)(6) mandates that the "time out room shall be unlocked and the door able to be opened from the inside." This information must be provided to any child who might be placed within the time out room.

Section 200.22(c)(7) mandates that "staff" be assigned to continuously monitor the student in a time out room. The federal mandate with respect to seclusion/time out rooms indicate that a trained clinician must continually monitor and assess the individual's physical and psychological status by being inside or immediately outside the seclusion room. Moreover, after the individual is removed from seclusion, a physician or licensed practitioner who is trained in emergency safety interventions must assess the individual's well-being. 42 C.F.R. 482.13. The "emergency regulations" do not specify what staff member is to be assigned; nor does it specify the level of clinical training, if any, that must be possessed by any staff member assigned to continuously monitor the student who has been placed in seclusion.

The "Emergency Regulations" Contradict Similar Federal Regulations Concerning Restraint and Seclusion Techniques In Many Important Respects

For individuals under 21 in federally-funded residential settings, governing federal regulations mandate that "[e]ach resident has the right to be free from restraint or seclusion, of any form, used as a means of coercion, discipline, convenience, or retaliation." 42 C.F.R. Ch. IV Subpart G. Yet, New York's "emergency regulations" permits restraints and time out rooms to be used as a means of discipline or coercion.

Governing federal regulations, and the policies of all major mental health commissions and agencies, mandate that restraint and seclusion should NEVER be used as punishment. 42 C.F.R. 482.13. Yet, New York's "emergency regulations" allow schools to use restraint and seclusion/time out rooms as punishment.

Federal regulations mandate that restraint and seclusion can only be used for genuine safety emergencies, and that the restraint or seclusion must be terminated as soon as the emergency subsides. 42 C.F.R. 482.13. New York's "emergency regulations" allow schools to plan to use restraints and time-out rooms for non-emergency situations. The regulations do not limit how long a child can be put in restraint or a time-out room. Section 200.22 authorizes the use of restraint techniques upon a child in non-emergency situations where it is included in that child's IEP. The danger of the proposed legislation is that restraint techniques will be used in non-emergency situations and will lead to the unwarranted and inappropriate use of restraint techniques.

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Under all of such circumstances, we believe that any New York State legislation with respect to the use of restraint techniques limit further or eliminate entirely the use of aversive interventions and seclusion and restraint techniques -- not expand the practice as these emergency regulations would permit.

We urge you to revoke these misguided "emergency" regulations. The permanent adoption of a regime which permits adversive behavioral interventions and seclusion and restraint techniques to be used on disabled children attending school in New York State would signal a retreat by New York State from its leadership role in the forefront of the national reform effort in this area. Rather we ask that you endorse a wiser course of action by both banning the use of adversive behavioral interventions and seclusion techniques and if not entirely eliminating at least limiting to emergency circumstances only the use of restraint techniques on students attending school in New York State. We also urge you to assure that New York State schools are more adequately staffed by individuals who are fully trained in the latest, most appropriate, positive behavioral approaches.

In closing, I want to make clear that my testimony and the accompanying written statement are not intended as a complete or exhaustive analysis of the amendments to section 19.5 of the Rules of the Board of Regents and the amendments to sections 200.1, 200.4 and 200.7 and new section 200.22 of the Regulations of the Commissioner of Education, relating to behavioral interventions. I have attempted to identify the NYCLU's principal concerns regarding the fundamental policy considerations that must be addressed before finalizing these major regulatory revisions. We appreciate the opportunity to express these views before you and we would welcome the opportunity to elaborate upon our analysis as the Board of Regents considers this critical initiative. Thank you.

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